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## Stories of Hope: Epidermolysis Bullosa



Chuck and Christine Anderson were butterfly children.

Born with an inherited condition that made their skin as fragile as a butterfly wing, Chuck died at 27 of skin cancer. His sister, Christine, died of heart failure at 14.

"These children taught me an incredible lesson in resilience, determination and good cheer," says their mother, **Lynn Anderson**. She is the president and founder of the Epidermolysis Bullosa Research Foundation.

They were born with the recessive form of dystrophic epidermolysis bullosa. "The glue that holds the skin together is missing," Anderson explains. "The skin tears or blisters at the slightest provocation."

Things as simple as putting on a shoe can cause chronic wounds. "Stiff pants make blisters. Pull on the arm, and the skin comes off," she says.

"Imagine not being able to swallow because you have scarring in your esophagus. You have difficulty eating because you have sores in your mouth," she says. The disease brings chronic anemia, malnutrition and growth retardation because most nutrition goes toward skin repair. When Chuck Anderson was 27, he weighed 59 pounds.

Anderson says she has great hopes for EB research. She is grateful for the researchers "who have helped my children's suffering come to something good, who have helped me believe that EB is not forever."

- Watch the Spotlight on Epidermolysis Bullosa talks
- Read about CIRM funding for Epidermolysis Bullosa research

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